

## **THE EXPERIENCES AND NEEDS OF FAMILIES OF PATIENTS WITH TRAUMATIC BRAIN INJURY: A QUALITATIVE SYSTEMATIC REVIEW**

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### **ABSTRACT**

The effect of TBI has been described as one of the greatest challenges to both the injured patients and families (Tomberg et al., 2007, Pierce and Hanks, 2006, Hart et al., 2003). Families of TBI patients have attracted the interest of many disciplines (Allen et al., 1994, Anderson et al., 2002, Carnevale et al., 2002) to conduct research on their experiences and needs.

Concerning the urgency of supporting a TBI patient's family, the type of participants of this systematic review protocol has been modified. Similarly, in the range of severity measurement by GCS and PTA, MS-TBI, this acronym, MS-TBI, will then be used for short, moderate and severe TBI. This might have experienced similar problems and persisted for an unpredictable time (Codd et al., 2011, Mills, 2009, Hawley, 2003, Hawley and Joseph, 2008). Almost seventy per cent of MTBI patients and their families face the same difficulties as STBI patients (Dikmen et al., 2003). Generally, this review will concern both MS-TBI patients' family needs.

In spite of the fact that a well conducted systematic review (SR) generates quality evidence in clinical practice (Lugtenberg et al., 2009, Moher et al., 2011, Squires et al., 2011), there is no such qualitative review of MS-TBI patients' families' needs during and after hospitalisation to be found in the Joanna Briggs Institute libraries nor quantitative has been retrieved in the Cochrane library. Due to the importance of exploring TBI patients' families' needs, to help families cope with brain damage, a qualitative SR on that topic needs to be conducted.

**KEYWORDS:** Families of Patients with Traumatic Brain Injury, GCS and PTA, MS-TBI

### **INTRODUCTION**

#### **Methodology**

The search for the current review was retrieved from February until July 2012. An initial search started in the JBI, The Campbell Collaboration and The NHS Centre for Research and Dissemination databases for qualitative systematic reviews on families' needs and TBI patients. This was followed by search in the bibliographies of major electronic databases such as CINAHL, MEDLINE Ovid, MEDLINE Proquest, Cirrie, BNI, PsycInfo, Web of knowledge and Web of science.

The results of the final search in each database were pooled into Endnote X5 and duplications were eliminated. Similarly, wholly relevant papers needed to be screened systematically; the first selection excluded the title of the studies, and the second by abstract. During this process, several abstracts might not reveal adequate information on methodology, method and participants. Consequently, articles without abstract held in reserve, were searched for full text evaluation.

## Quality Assessment

The standardised critical appraisal tool of the Joanna Briggs Institute (JBI) for qualitative assessment and review instrument (QARI) was used to manage, appraise, extract and synthesise qualitative data as part of a systematic review of evidence. Criteria 1-5 in the JBI quality appraisal tool, dealt with congruence between philosophy, methodology and analysis was applied for this SR (JBI, 2004).

## Data Extraction

The data extracted includes methodology, method, phenomena of interest, setting, geographical, cultural, participants, data analysis, authors conclusion and reviewers comments. Data extraction involves transferring data from the original paper using an approach agreed upon and standardised for the specific review. Accordingly, analysis and synthesis is processed by QARI software data extraction instrument 2011

## Data Synthesis

All data results were classified hierarchal. The first hierarchy of evidence is unequivocal. The second credible evidence is plausible in the light of the data and theoretical framework. The last hierarchy is unsupported.

## FINDINGS

After examining 374 titles and abstracts, 59 studies appeared eligible for this review and, thus, the full articles were retrieved. After the completed papers were received and compared to the eligibility criteria for this review, 47 studies were excluded for the following reasons; methodology and/or method irrelevant (n=20). Acquired brain injury severity qualification was not classified (n=10); family, patient and HPs experience on needs was not classified (n=9), family needs were not separated based on brain injury severity level.

**Table 1: Characteristics of Including Studies**

No	Study	Methodology Method Data Analysis	Country Context	Setting Place	Participants	Patients	Cause of TBI
					Age	Level of TBI Age	
1	Bond et al., (2003)	<ul style="list-style-type: none"> <li>Exploratory descriptive qualitative</li> <li>Semi-structured interview</li> <li>Content analysis</li> </ul>	USA	Neurosurgical-ICU	<ul style="list-style-type: none"> <li>2 Mothers</li> <li>1 Daughter</li> <li>1 Father</li> <li>1 Grandmother</li> <li>1 Sister</li> <li>2 Uncle</li> <li>41-61</li> </ul>	<ul style="list-style-type: none"> <li>STBI</li> <li>Above 18</li> </ul>	<ul style="list-style-type: none"> <li>Fall</li> <li>Gun-shoot</li> <li>Car accident</li> </ul>
2	Duff(2002)	<ul style="list-style-type: none"> <li>Grounded theory</li> <li>Open-ended interview</li> <li>Constant comparative analysis</li> </ul>	Canada	Acute care neurosurgical unit	<ul style="list-style-type: none"> <li>6 Mothers</li> <li>7 Fathers</li> <li>1 Daughter</li> <li>2 Sons</li> <li>3 Sisters</li> <li>3 Brothers</li> <li>1 Aunt</li> <li>1 Daughter in law</li> <li>1 Grandchild</li> <li>18 and over</li> </ul>	<ul style="list-style-type: none"> <li>STBI</li> <li>18-86</li> </ul>	<ul style="list-style-type: none"> <li>Vehicle collision</li> <li>Pedestrian/vehicle collision</li> <li>falls</li> </ul>
3	Fleming et al., (2012)	<ul style="list-style-type: none"> <li>Phenomenology</li> <li>Semi-structured interview</li> <li>Content analysis</li> </ul>	Australia	Brain injury rehabilitation unit	<ul style="list-style-type: none"> <li>11 Spouses</li> <li>6 Parents</li> <li>1 Daughter</li> <li>24-65</li> </ul>	<ul style="list-style-type: none"> <li>STBI</li> <li>17-63</li> </ul>	<ul style="list-style-type: none"> <li>Motor vehicle accident</li> <li>Assault</li> <li>Fall</li> </ul>
4	Jumisko et al., (2007)	<ul style="list-style-type: none"> <li>Phenomenology</li> <li>Semi-structured interview</li> <li>Content analysis</li> </ul>	Sweden	Participant's home	<ul style="list-style-type: none"> <li>2 Mothers</li> <li>1 Father</li> <li>2 Partners</li> <li>2 Siblings</li> <li>1 Daughter</li> <li>28-56</li> </ul>	<ul style="list-style-type: none"> <li>MS-TBI</li> <li>25-30</li> </ul>	<ul style="list-style-type: none"> <li>Traffic accident</li> <li>Fall</li> </ul>
5	Kean (2010)	<ul style="list-style-type: none"> <li>Grounded theory</li> <li>Open-ended interview</li> </ul>	UK	ICU	<ul style="list-style-type: none"> <li>6 Husbands/Fathers</li> <li>3 Son/Brother</li> <li>12-56</li> </ul>	<ul style="list-style-type: none"> <li>MS-TBI</li> <li>17-63</li> </ul>	<ul style="list-style-type: none"> <li>Traffic accident</li> <li>Fall</li> </ul>

		▪ Constant comparative analysis					
6	Keenan and Joseph (2010)	▪ Phenomenology ▪ Semi-structured interview, open-ended question and demographic information ▪ Thematic analysis	Canada	ICU, rehabilitation and complex care settings.	▪ 9 Mothers ▪ 3 Fathers ▪ 5 Wives ▪ 4 Sisters ▪ 3 Girlfriends ▪ 1 Brother ▪ 16-65	▪ STBI ▪ 17-58	▪ Motor vehicle collision ▪ Fall
7	Lefebvre et al., (2005)	▪ Phenomenology ▪ Semi-structured interview ▪ Content analysis	Canada	Participant's home	▪ 9 Parents ▪ 1 Spouse ▪ 3 Siblings ▪ 1 other ▪ 18-60	▪ MS-TBI ▪ 17-63	Cerebral assault by an external physical force
8	Lefebvre et al., (2008)	▪ Qualitative study ▪ Semi-structured interview ▪ Content analysis	Canada	Participant's home	▪ 6 Fathers/mothers ▪ 2 Siblings ▪ 5 Friends ▪ 2 Partners ▪ 8 Spouse ▪ 1 Resources at the residential care centre ▪ 18 to over 50	▪ MS-TBI ▪ 40-49	Trauma
9	Leith et al., (2004)	▪ Exploratory descriptive qualitative ▪ Semi-structured focus group interview ▪ Thematic analysis	USA	Participant's home	▪ 6 Married ▪ 1 Divorced ▪ 3 Single  ▪ 33 to 67	▪ MS-TBI ▪ 35-37	Traffic accident
10	Liddle et al., (2011)	▪ Phenomenology	Australia	Participant's home	▪ 6 Parents ▪ 3 Spouses	▪ MS-TBI ▪ 21-63	▪ Vehicle accident
		▪ Semi-structured interview ▪ Content analysis			▪ 18 and over		▪ Fall ▪ Assault
11	Moreno et al., (2011)	▪ Grounded theory ▪ Semi-structured interview, open-ended question and demographic information ▪ Line by line analysis	UK	Participant's home	▪ 6 Daughters ▪ 3 Sons ▪ 12-20	▪ STBI ▪ Not reported	▪ Car accident ▪ Sport accident
12	Wongvatunyu and Porter (2005)	▪ Phenomenology ▪ Semi-structured interview ▪ Content analysis	USA	Participant's home	▪ 7 Mothers ▪ 46-64	▪ MS-TBI ▪ 20-36	▪ Traffic accident ▪ Fall

Table 2: Characteristics of Including Studies

No	Study	Methodology Method Data Analysis	Country context	Setting Place	Participants	Patients	Cause of TBI
					Age	Level of TBI Age	
1	Bond et al., (2003)	▪ Exploratory descriptive qualitative ▪ Semi-structured interview ▪ Content analysis	USA	Neurosurgical-ICU	▪ 2 Mothers ▪ 1 Daughter ▪ A Father ▪ 1 Grandmother ▪ 1 Sister ▪ 2 Uncle ▪ 41-61	▪ STBI ▪ Above 18	▪ Fall ▪ Gun-shoot ▪ Car accident
2	Duff (2002)	▪ Grounded theory ▪ Open-ended interview ▪ Constant comparative analysis	Canada	Acute care neurosurgical unit	▪ 6 Mothers ▪ 7 Fathers ▪ 1 Daughter ▪ 2 Sons ▪ 3 Sisters ▪ 3 Brothers ▪ 1 Aunt ▪ 1 Daughter in law ▪ 1 Grandchild ▪ 18 and over	▪ STBI ▪ 18-86	▪ Vehicle collision ▪ Pedestrian/vehicle collision ▪ falls
3	Fleming et al., (2012)	▪ Phenomenology ▪ Semi-structured interview ▪ Content analysis	Australia	Brain injury rehabilitation unit	▪ 11 Spouses ▪ 6 Parents ▪ 1 Daughter ▪ 24-65	▪ STBI ▪ 17-63	▪ Motor vehicle accident ▪ Assault ▪ Fall
4	Jumisko et al., (2007)	▪ Phenomenology ▪ Semi-structured interview ▪ Content analysis	Sweden	Participant's home	▪ 2 Mothers ▪ 1 Father ▪ 2 Partners ▪ 2 Siblings ▪ 1 Daughter ▪ 28-56	▪ MS-TBI ▪ 25-30	▪ Traffic accident ▪ Fall
5	Kean (2010)	▪ Grounded theory ▪ Open-ended interview	UK	ICU	▪ 6 Husbands/Fathers ▪ 3 Son/Brother ▪ 12-56	▪ MS-TBI ▪ 17-63	▪ Traffic accident ▪ Fall

		<ul style="list-style-type: none"> <li>Constant comparative analysis</li> <li>Phenomenology</li> </ul>					
6	Keenan and Joseph (2010)	<ul style="list-style-type: none"> <li>Semi-structured interview, open-ended question and demographic information</li> <li>Thematic analysis</li> </ul>	Canada	ICU, rehabilitation and complex care settings.	<ul style="list-style-type: none"> <li>9 Mothers</li> <li>3 Fathers</li> <li>5 Wives</li> <li>4 Sisters</li> <li>3 Girlfriends</li> <li>1 Brother</li> <li>16-65</li> </ul>	<ul style="list-style-type: none"> <li>STBI</li> <li>17-58</li> </ul>	<ul style="list-style-type: none"> <li>Motor vehicle collision</li> <li>Fall</li> </ul>
7	Lefebvre et al., (2005)	<ul style="list-style-type: none"> <li>Semi-structured interview</li> <li>Content analysis</li> </ul>	Canada	Participant's home	<ul style="list-style-type: none"> <li>9 Parents</li> <li>1 Spouse</li> <li>3 Siblings</li> <li>1 other</li> <li>18-60</li> </ul>	<ul style="list-style-type: none"> <li>MS-TBI</li> <li>17-63</li> </ul>	Cerebral assault by an external physical force
8	Lefebvre et al., (2008)	<ul style="list-style-type: none"> <li>Qualitative study</li> <li>Semi-structured interview</li> <li>Content analysis</li> </ul>	Canada	Participant's home	<ul style="list-style-type: none"> <li>6 Fathers/mothers</li> <li>2 Siblings</li> <li>5 Friends</li> <li>2 Partners</li> <li>8 Spouse</li> <li>1 Resources at the residential care centre</li> <li>18 to over 50</li> </ul>	<ul style="list-style-type: none"> <li>MS-TBI</li> <li>40-49</li> </ul>	Trauma
9	Leith et al., (2004)	<ul style="list-style-type: none"> <li>Exploratory descriptive qualitative</li> <li>Semi-structured focus group interview</li> <li>Thematic analysis</li> </ul>	USA	Participant's home	<ul style="list-style-type: none"> <li>6 Married</li> <li>1 Divorced</li> <li>3 Single</li> <li>33 to 67</li> </ul>	<ul style="list-style-type: none"> <li>MS-TBI</li> <li>35-37</li> </ul>	Traffic accident
10	Liddle et al., (2011)	<ul style="list-style-type: none"> <li>Phenomenology</li> <li>Semi-structured interview</li> </ul>	Australia	Participant's home	<ul style="list-style-type: none"> <li>6 Parents</li> <li>3 Spouses</li> <li>18 and over</li> </ul>	<ul style="list-style-type: none"> <li>MS-TBI</li> <li>21-63</li> </ul>	<ul style="list-style-type: none"> <li>Vehicle accident</li> <li>Fall</li> <li>Assault</li> </ul>
		<ul style="list-style-type: none"> <li>Content analysis</li> <li>Grounded theory</li> </ul>					
11	Moreno et al., (2011)	<ul style="list-style-type: none"> <li>Semi-structured interview, open-ended question and demographic information</li> <li>Line by line analysis</li> </ul>	UK	Participant's home	<ul style="list-style-type: none"> <li>6 Daughters</li> <li>3 Sons</li> <li>12-20</li> </ul>	<ul style="list-style-type: none"> <li>STBI</li> <li>Not reported</li> </ul>	<ul style="list-style-type: none"> <li>Car accident</li> <li>Sport accident</li> </ul>
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## DISCUSSIONS

There are three meta-syntheses; every theme relates to the others. This inter-relation of need might well be experienced by families through their entire lives, and it begins by TBI relatives being admitted until re-entry into the community. As a whole, three syntheses then will be re-interpreted to capture the essence of this SR phenomenon of interest.

**Table 3: A Meta-Synthesis Experience and Needs of TBI Patient's Family**

Meta-synthesis	Synthesis	Findings
Experiences and needs of TBI patients' families	A consistent, continued comprehensive information and education and to have opportunities to be involved in care. Family help family to experience resourcefulness and empowerment to cope with brain damage	<ul style="list-style-type: none"> <li>Need for information, education, involvement in care, feeling of resourcefulness and empowerment as perceived by family</li> <li>The earlier days' family experience of their TBI relative</li> </ul>
	Families faced struggles to adapt with TBI and need consistent, continuous and comprehensive professional support to cope with TBI and its consequences	<ul style="list-style-type: none"> <li>Family adaptation process to live with TBI person</li> <li>Professional support needs by families for their TBI person as well as to adapt to change caused by TBI</li> </ul>
	Strong support from peers, extended family and society, to help families to successfully re-enter community and continue a normal life as well	<ul style="list-style-type: none"> <li>Inter-family relationships after one of family member got TBI</li> <li>Peer, extended family relationship and society as perceived by families helped re-enter community</li> </ul>

### **Information, Education, Involvement in Care, Feeling of Resourcefulness and Empowerment as Perceived by Families**

The first synthesis is that during the hospitalisation period families face dramatic change in two places; hospital and home environment where families have insufficient information, education, involvement in care and resources of TBI. As it has been reported in a recent study, families need to know everything about their relative's condition (Bond et al., 2003) from the very beginning that they were admitted to hospital. Accordingly, there are several issues regarding the earlier information as perceived by family. Bond et al (2003) have reported that during the 24-48 hours after their TBI relative was admitted to ICU, the family experienced a lack of concentration as to what doctors said about their relative's condition. This might result in different interpretations between family as receiver and doctor as messenger. These variations may then result in differences of family perspectives on information needs.

According to Hergie (2011) the way is to transfer information from messenger to receiver (Hergie, 2011), from not knowing anything then knowing something. Information can be delivered verbally or non-verbally. To successfully deliver information, a good interpersonal communication skill seems to be one of the answers that every HP should have (Hugman, 2009, Bach and Grant, 2011). Further, one thing that needs to be concerned by HPs is medical vocabulary. Common words will be easier for families to understand than medical terms. Another solution is a two-way communication. This enables family to have a better and clearer understanding.

### **Consistency, Continuity and Comprehensive Professional Support**

In the second synthesis, families' face a struggle to adapt with TBI and need consistent, continuous and comprehensive professional support to cope with TBI and its consequences. As it has been reported by Duff (2006) TBI causes a dramatic change in families (Duff, 2006) and has impacted on the family structure. The effect of TBI does not only need HPs support but also other professionals as well. However, little attention has been given to the problems of families as individuals, sub-groups, or as a family unit. From the evidence, family appraisal, family capacity or resilience and the process of family adaptation to living with TBI seems not to have been a part of professionals' work objectives.

The deficiency of long-term professional support might result from the fact that most services available (Rotondi et al., 2007) to persons with TBI occur during acute and inpatient care. However, from all included papers, only a few families have access to TBI professional support (Degeneffe and Olney, 2010). The availability of this service varies with regard to funding and public health service programming for long-term support for people with TBI and their families, for example in the USA (Leith et al., 2004) and in Australia (Liddle et al., 2011). Generally, even in developed countries, not all professional support which is needed by TBI patients and their families, is widely available and fully funded.

In daily life after discharge, families may play a role as a caregiver while family caregiving is the unpaid work of a family member to help another family member. To some extent, families need expert guidance as they begin to receive the impact of injury (Duff, 2006). To support family as a caregiver, consistent, continuous and comprehensive professional support is strongly needed. However, Crow and Pierce (2005) argued that this service should be widely available and free because finding funding for TBI service is a huge undertaking requiring time and energy to find. This complex problem seems a strong issue to discuss as a policy in healthcare.

### Support from Peer, Extended Family and Society

The third synthesis is that families with a TBI person who had strong support from peers, extended family and society might have successfully re-entered their community and continued a normal life as well. This particular support has also contributed to inter-family relationships. Close family who experienced the burden because of TBI might need to be listened to and received emotional support from their peers and/or extended families.

The evidence suggests that support of peers and extended families helps families to fight the feeling of “losing one’s foothold” (Jumisko et al., 2007, Moreno-Lopez et al., 2011, Kean, 2010). Families were forced to relinquish the life they had planned and instead had to find new ways of living with a changed person. The loss of this familiar life entailed great suffering.

Although some families experienced social barriers to re-gain their normal lives after TBI, this might be associated with society lacking information with regard to TBI. In this case, the sovereignty of support from extended families and peers through their role as support resources for families, might help reduce the effect of this barrier to families of TBI members.

### Recommendation for Future Research

As previously acknowledged, the studies selected for this meta-synthesis present qualitative findings in developing countries. This raises the question of whether the different moments of time, health service availability, the characteristics of families’ needs, and the helping context or support should be given. However, it is not possible to draw such comparisons from this meta-synthesis and such issues on the similar phenomenon. Overall, a qualitative study in a developing country with a high level of TBI cases and a wide age range of family members as participants is highly recommended for further consideration.

### CONCLUSIONS

This SR is condensed from the best evidence; these three meta-syntheses should be taken into account when planning, developing, or updating HE for TBI patients’ families during the hospitalisation period. Hence, the result of this SR will not only benefit both of them but also there will be a transformational leadership process for families to be leaders in the changes to their lives caused by MS-TBI.

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